



**LEGISLATION AND PUBLIC POLICY
COMMITTEE (LPPC)
MEETING NOTICE/AGENDA**

Posted at www.scdd.ca.gov

DATE: January 24, 2013

TIME: 10:30 a.m. – 3:00 p.m.

LOCATION: State Council on Developmental Disabilities
1507 21st Street, Suite 210
Sacramento, CA 95811
916/322-8481

TELECONFERENCE SITES:

Area Board 7

2580 North First Str, Ste 240
San Jose, CA 95131

Area Board 9

200 East Santa Clara Str, Ste 210
Ventura, CA 93001

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in the meeting, should contact Michael Brett at 916/322-8481 or michael.brett@scdd.ca.gov by 5p on January 17, 2013.

Page

1. **CALL TO ORDER**

R. Ceragioli

2. **ESTABLISHMENT OF QUORUM**

R. Ceragioli

- | | | | |
|----|-------------------------------------|--------------|---|
| 3. | WELCOME AND INTRODUCTIONS | R. Ceragioli | |
| 4. | APPROVAL OF 10/17/12 MINUTES | R. Ceragioli | 3 |
| 5. | PUBLIC COMMENTS | | |

*This item is for members of the public only to provide comments and/or present information to the Committee on matters **not** on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first. The Committee will provide a public comment period, not to exceed a total of seven minutes, for public comment prior to action on each agenda item.*

6. STATE BUDGET UPDATE

- | | | |
|--|----------|---|
| A. Governor's January 10 Budget Proposal | M. Polit | 5 |
|--|----------|---|

7. STATE LEGISLATIVE ISSUES

- | | | |
|--|-----------------|----|
| A. Current Legislature and Committee Structure | K. Alipourfard. | |
| B. State Council Sponsored Legislation | M. Polit | |
| C. SB 946 Implementation Follow Up | A. Bacigalupo | 13 |
| D. Equity in Delivery of Services | B. Wheeler | |
| E. Pending Legislation | M. Polit | |
| F. Other Legislative Issues | M. Polit | |

8. FEDERAL LEGISLATIVE ISSUES

- | | | |
|---|-----------------|----|
| A. Current California Congressional Delegation | K. Alipourfard. | |
| B. Federal Budget Update | M. Polit | |
| C. Convention on the Rights of People with Disabilities | J. Allen | 15 |

9. DEVELOPMENTAL CENTER ISSUES

- | | | |
|---------------------------------------|-----------------------|----|
| A. Sonoma Developmental Center Update | H. Bins
R. Philips | 97 |
| B. Lanterman Closure Update | M. Polit | |
| C. Related Legislative Issues | M. Polit | |

10. ADJOURNMENT

R. Ceragioli

DRAFT
Legislative & Public Policy (LPPC) Committee Minutes
Wednesday, October 17, 2012

Members Present

Leroy Shipp, Acting Chair
Jennifer Allen
Marilyn Barraza
Lisa Cooley
Connie Lapin
April Lopez
David Mulvaney

Members Absent

Ray Ceragioli, Chair
Tho Vinh Banh
Dan Boomer
Margaret Shipp

Others Present

Evelyn Abouhassan
Karim Alipourfard
Christofer Arroyo
Mark Polit

1. CALL TO ORDER

Leroy Shipp, Acting Chairperson, called the meeting to order at 10:33 AM.

2. ESTABLISHMENT OF A QUORUM

A quorum was established.

3. INTRODUCTIONS AND ANNOUNCEMENTS

Members introduced themselves and announcements were made.

4. APPROVAL OF 5/24/12 MINUTES

It was moved, seconded (Lapin/Barraza), and carried to approve the LPPC minutes as written.

5. PUBLIC COMMENTS

There were no public comments.

6. LEGISLATIVE ISSUES

A summary of bills from the 2011-2012 legislative session was reviewed.

Employment First Policy: AB 2338 (Chesbro), sponsored by SCDD, was held in Senate Appropriations Committee. Council staff can work with

Chesbro and other supporting organizations to better position Employment First for passage next year. It was moved, seconded (Cooley/Allen), and carried for the Council to sponsor a bill to establish an Employment First Policy in law.

Self-Determination: Many areas of interest were expressed regarding the Council sponsoring future legislation. It was moved, seconded (Lapin/Barraza), and carried for the Council to explore sponsoring a bill on self-determination.

State and Federal Budget Impacts: An update regarding the state budget, state propositions, and federal sequestration were reviewed. If Congress and the Obama Administration does not act before January, automatic cuts of 8.2% will take place across much of federal non-entitlement spending, including the Federal DD Act, which funds Council operations, the UCEDDs, and DRC. It was moved, seconded (Lapin/Allen), and carried for the Council to write the California Congressional delegation, inform them of the impact that these cuts would have on individuals with developmental disabilities, and for the Council to oppose those measures.

The legislative report was briefly reviewed and provided to the LPPC.

RC Conflict of Interest (COI) Regulations: Current statute requires Area Boards and SCDD to review COI waivers for regional center board members, but not for regional center executive directors. The proposed regulations require Area Board and SCDD review for both RC board members and executive directors. After discussion, it was moved, seconded (Lapin/Barraza), and carried for the Council to provide input on the regulations to DDS so that the statutory and regulatory language that requires local area boards and the Council to approve the conflict of interest waivers is removed and to provide additional comments and recommendations consistent with the LPPC COI detail sheet.

The state legislative process to approve bills into laws was reviewed. Discussion ensued.

7. AREA BOARD LEGISLATIVE UPDATES

No report.

8. ADJOURNMENT

The meeting was adjourned at 3:01 PM.

Department of Developmental Services

Governor's Budget Highlights



**Edmund G. Brown Jr.
Governor
State of California**

**Diana S. Dooley
Secretary
California Health and Human Services Agency**

**Terri Delgadillo
Director
Department of Developmental Services**

January 2013

DEPARTMENT OF DEVELOPMENTAL SERVICES GOVERNOR'S BUDGET HIGHLIGHTS

PROGRAM HIGHLIGHTS

The Department of Developmental Services (the Department) is currently responsible under the Lanterman Developmental Disabilities Services Act (Lanterman Act) for ensuring that 258,424 persons with developmental disabilities receive the services and support they require to lead more independent and productive lives and to make choices and decisions about their lives.

California provides services and supports to individuals with developmental disabilities in two ways: the vast majority of people live in their families' homes or other community settings and receive state-funded services that are coordinated by one of 21 non-profit corporations known as regional centers. A small number of individuals live in four state-operated developmental centers and one state-operated community facility. The number of consumers with developmental disabilities in the community served by regional centers is expected to increase from 256,872 in the current year to 266,100 in Fiscal Year (FY) 2013-14. The number of individuals living in state-operated residential facilities will be 1,186 by the end of FY 2013-14.

The January 2013 Governor's Budget includes \$4.9 billion total funds (\$2.8 billion General Fund) for the Department in 2013-14; a net increase of \$178.7 million above the revised 2012-13 budget, a 3.8 percent increase; and \$193.1 million above the 2012-13 enacted budget.

COMMUNITY SERVICES PROGRAM

2012-13

To provide services and support to 256,872 persons with developmental disabilities in the community, the Governor's Budget updates FY 2012-13 funding to \$4.2 billion total funds (\$2.3 billion GF). The Governor's Budget includes an increase of \$20.2 million total funds (-\$18.9 million GF decrease) for regional center operations (OPS) and purchase of services (POS). This is composed of:

Caseload and Utilization

\$36.0 million increase (-\$3.0 million GF decrease) in regional center OPS and POS costs due to updated caseload and expenditure data including Home and Community Based Services (HCBS) waiver enrollment above budgeted levels.

Impacts from Other Departments

-\$30.8 million decrease GF in POS to reflect the Department of Health Care Services (DHCS) withdrawal of implementation of Medi-Cal copayments for physician and dental office visits, emergency room visits, and hospital inpatient days.

Copayments for Health Care Related Services

\$15.0 million increase GF to reflect increased expenditures associated with a recent regional center legal opinion that is expected to change regional center practices regarding funding of health insurance copayments and deductibles.

2013-14

The Governor's Budget projects an average community caseload of 266,100 individuals in the budget year, an increase of 10,128 consumers over the enacted budget. The estimate proposes 2013-14 funding for services and support to persons with developmental disabilities in the community at \$4.3 billion total funds (\$2.5 billion GF), an increase of \$203.5 million (\$140.2 million GF) over the enacted 2012-13 budget. The regional center budget changes include:

Caseload and Utilization

\$177.5 million (\$89.2 million GF) increase in regional center OPS and POS due to updated caseload and expenditure data including HCBS waiver enrollment above budgeted levels.

Sunset of 1.25 Percent Payment Reduction

\$46.7 million (\$31.9 million GF) increase in OPS and POS to reflect the June 30, 2013 sunset of the 1.25 percent payment reduction.

Impacts from Other Departments

-\$30.8 million decrease GF in POS to reflect the DHCS withdrawal of implementation of Medi-Cal copayments for physician and dental office visits, emergency room visits, and hospital inpatient days.

Copayments for Health Care Related Services

\$9.9 million increase GF to reflect increased expenditures associated with a recent regional center legal opinion that is expected to change regional center practices regarding funding of health insurance copayments and deductibles. Proposed statute will limit the funding of health insurance copayments based on the family's ability to pay, modeled after existing programs, and prohibit the payment of deductibles.

Fund Shift:

\$40.0 million fund shift from the California First Five Commission (Proposition 10) to GF for a net program change of \$0.0 million.

Quality Assurance Fee (QAF)

\$0.2 million increase (\$0.0 million GF) in POS to reflect updated administration and service expenditures for day treatment and transportation costs of ICF-DD residents.

DEVELOPMENTAL CENTERS PROGRAM

2012-13

To provide services and support for 1,552 residents in developmental centers (average in-center population) the Governor's Budget updates FY 2012-13 funding to \$545.1 million (\$283.8 million GF), a decrease of \$5.1 million (\$2.4 million GF) over the FY 2012-13 enacted budget. Authorized positions decrease by 2.5. The developmental center budget changes include:

- Savings Shift of \$2.9 million from Operating Expenses and Equipment (OE&E) to Personal Services (PS) based on a reduction of -36.0 positions driven by admissions and residential program reductions, and increased placements. The 2012 May Revision reflected a net decrease of \$9.1 million which represented the DC's portion of the \$200 million General Fund Savings Solutions. The Department initially displayed the savings in OE&E. This fund shift more accurately reflects the savings solutions as partially funded through position reductions.
- Net decrease of \$7.2 million (\$3.6 million GF) due to changes in State employee retirement and health benefit rates, and employee compensation reductions.
- \$2.1 million (\$1.3 million GF) and 33.5 position increase due to a higher than anticipated resident population on July 1, 2012, primarily based on fewer individuals transitioning from Lanterman Developmental Center to community settings. The increase includes \$1.7 million (\$0.9 million GF) and 27 positions in Level of Care (LOC) and \$0.4 million (\$0.3 million GF) and 6.5 positions in Non-Level of Care (NLOC).

2013-14

For FY 2013-14, the Governor's Budget provides services and support for 1,304 residents (average in-center population) in developmental centers, a decrease of 240 residents from the 2012-13 enacted budget. Funding decreases to \$539.0 million (\$279.3 million GF); a decrease of \$11.2 million (\$7.0 million GF) and authorized positions decreases to 4,768; a decrease of 388.5 positions below the enacted budget. By the end of the budget year there is expected to be 1,186 individuals residing in the state operated facilities. Adjustments to the enacted budget for the developmental centers include:

- -\$25.4 million (-\$14.4 million GF) and -352.5 position reduction due to the anticipated decrease of 223 residents primarily from the continuing transition of individuals into the community. Lanterman DC makes up almost half of the

residential decline as 110 individuals are expected to transition into community living arrangements in the budget year. This reduction, along with unit consolidations results in a reduction of -\$19.2 million (-\$11.0 million GF) and -245 positions in LOC and -\$6.2 million (-\$3.4 million GF) and -107.5 positions NLOC.

- Savings shift of \$2.9 million from OE&E to Personal Services (PS) based on a reduction of -36.0 positions and -17 residents driven by admissions and residential program reductions, and increased placements. The 2012 May Revision reflected a net decrease of \$9.1 million which represented the DC's portion of the \$200 million General Fund Savings Solutions. The Department initially displayed the savings in OE&E. This fund shift more accurately reflects the savings solutions.
- Net increase of \$11.9 million (\$6.2 million GF) due to changes in State employee retirement and health benefit rates, and employee compensation. Savings associated with the personal leave program (PLP) are not reflected in 2013-14 as most bargaining agreements expire at the end of this FY.
- \$2.4 million (\$1.3 million GF) for additional staff on residential units to ensure the supervisors (shift leads) on 10 ICF units are able to oversee and support the employees delivering direct care which are critical to the health and safety of residents. This change was necessary to help address licensing concerns regarding staffing levels.

LANTERMAN DEVELOPMENTAL CENTER CLOSURE UPDATE

The Governor's Budget continues to support Developmental Center and Community efforts towards closure of the Lanterman facility. The Department, working with regional centers, anticipates the transition of approximately 110 Lanterman Developmental Center (Lanterman) residents in FY 2012-13 consistent with the enacted budget. The Governor's Budget anticipates the transition of another 110 residents to community living arrangements in FY 2013-14.

- The Governor's Budget retains \$0.7 million (\$0.5 million GF) and 25.0 positions in 2012-13:
 - \$2.0 million (\$1.1 million GF) and 27.0 positions are retained (24 positions and \$1.9 million LOC and 3 positions and \$0.1 million NLOC) to reflect an additional 20 residents at Lanterman at the beginning of the year based on fewer residential placements in 2011-12.
 - Reduction of -2.0 positions associated with the fund shift from OE&E to personal services to more accurately reflect the previous \$200 million General Fund Savings Solutions detailed above.
 - -\$1.3 million (-\$0.6 million GF) reduction due to changes in State employee retirement and health benefit rates, and employee compensation.

- The Governor's Budget reflects a net decrease in 2013-14 of -\$10.3 million (\$-5.7 million GF) and -178.0 positions:
 - -\$12.4 million (-\$6.8 million GF) reduction and -178.0 fewer positions due to the anticipated decline in the average in-center population from 184 to 85 residents, as compared to the enacted budget. This includes a reduction of -111 positions and -\$8.6 million in LOC and -65 positions and -\$3.8 million in NLOC.
 - \$2.1 million (\$1.1 million GF) increase due to changes in State employee retirement and health benefit rates, and employee compensation. Savings associated with the personal leave program (PLP) are not reflected in 2013-14 as explained above.

The Lanterman Closure Update Report and closure milestones will be released separately.

CAPITAL OUTLAY

The Governor's Budget does not include any new Capital Outlay requests.

HEADQUARTERS

2012-13

The Governor's Budget for FY 2012-13 updates funding for Headquarters' operations to \$37.8 million (\$24.2 million GF), a decrease of -\$0.7 million (-\$0.3 million GF) compared to the FY 2012-13 enacted budget. The Headquarters budget changes are due to changes in State employee retirement and health benefit rates, and employee compensation reductions.

2013-14

The Governor's Budget proposes headquarters operations funding for FY 2013-14 of \$39.3 million (\$25.0 million GF), an increase of \$0.8 million (\$0.5 million GF) compared to the FY 2012-13 enacted budget. The FY 2013-14 budget changes are due to changes in State employee retirement and health benefit rates, and employee compensation. Savings associated with the personal leave program (PLP) are not reflected in 2013-14 as explained above.

DEPARTMENT OF DEVELOPMENTAL SERVICES
2013-14 Governor's Budget

FUNDING SUMMARY

(Dollars in Thousands)

	2012-13	2013-14	Difference
BUDGET SUMMARY			
COMMUNITY SERVICES	\$4,166,367	\$4,349,632	\$183,265
DEVELOPMENTAL CENTERS	545,075	539,022	-6,053
HEADQUARTERS SUPPORT	37,796	39,280	1,484
TOTALS, ALL PROGRAMS	\$4,749,238	\$4,927,934	\$178,696
FUND SOURCES			
General Fund	\$2,604,142	\$2,759,396	\$155,254
Reimbursements: Totals All	2,092,322	2,117,716	25,394
<i>Medicaid (aka HCBS) Waiver</i>	1,129,428	1,169,109	39,681
<i>Medicaid (HCBS) Waiver Administration</i>	9,216	9,921	705
<i>Medicaid Administration (NHR)</i>	11,761	12,081	320
<i>Targeted Case Management</i>	138,693	142,347	3,654
<i>Targeted Case Management Admin.</i>	3,840	3,892	52
<i>Medi-Cal</i>	254,729	252,809	-1,920
<i>Title XX Block Grant</i>	225,060	225,060	0
<i>ICF-DD/State Plan Amendment</i>	52,915	55,630	2,715
<i>Quality Assurance Fees (DHCS)</i>	9,620	9,845	225
<i>California First Five Commission</i>	40,000	0	-40,000
<i>1915(i) State Plan Amendment</i>	161,804	169,122	7,318
<i>1915(k) Medicaid State Plan</i>	1,924	7,000	5,076
<i>Money Follows the Person</i>	14,867	14,867	0
<i>Homeland Security Grant</i>	57	391	334
<i>Race to the Top</i>	286	286	0
<i>Early Periodic Screening Diagnostic & Treatment</i>	11,793	16,516	4,723
<i>Other</i>	26,329	28,840	2,511
Federal Trust Fund	55,083	55,041	-42
Lottery Education Fund	465	465	0
Program Development Fund (PDF)	9,553	9,553	0
Mental Health Services Fund	1,129	1,128	-1
Developmental Disabilities Svs Acct	150	150	0
AVERAGE CASELOAD			
Developmental Centers	1,552	1,304	-248
Regional Centers	256,872	266,100	9,228
AUTHORIZED POSITIONS			
Developmental Centers	5,154.0	4,768.0	-386.0
Headquarters	374.5	374.5	0.0

**DEPARTMENT OF DEVELOPMENTAL SERVICES
2013-14 Governor's Budget**

(Dollars in Thousands)

	2012-13	2013-14	Difference
Community Services Program			
Regional Centers	\$4,166,367	\$4,349,632	\$183,265
Totals, Community Services	\$4,166,367	\$4,349,632	\$183,265
General Fund	\$2,296,105	\$2,455,125	\$159,020
Dev Disabilities PDF	9,267	9,267	0
Developmental Disabilities Svs Acct	150	150	0
Federal Trust Fund	52,006	52,006	0
Reimbursements	1,808,099	1,832,344	24,245
Mental Health Services Fund	740	740	0
Developmental Centers Program			
Personal Services	\$439,481	\$434,912	-\$4,569
Operating Expense & Equipment	105,594	104,110	-1,484
Total, Developmental Centers	\$545,075	\$539,022	-\$6,053
General Fund	\$283,837	\$279,264	-\$4,573
Federal Trust Fund	510	510	0
Lottery Education Fund	465	465	0
Reimbursements	260,263	258,783	-1,480
Headquarters Support			
Personal Services	\$33,353	\$34,880	\$1,527
Operating Expense & Equipment	4,443	\$4,400	-43
Total, Headquarters Support	\$37,796	\$39,280	\$1,484
General Fund	\$24,200	\$25,007	\$807
Federal Trust Fund	2,567	2,525	-42
PDF	286	286	0
Reimbursements	10,354	11,074	720
Mental Health Services Fund	389	388	-1
Totals, All Programs	\$4,749,238	\$4,927,934	\$178,696
Total Funding			
General Fund	\$2,604,142	\$2,759,396	\$155,254
Federal Trust Fund	55,083	55,041	-42
Lottery Education Fund	465	465	0
Dev Disabilities PDF	9,553	9,553	0
Developmental Disabilities Svs Acct	150	150	0
Reimbursements	2,078,716	2,102,201	23,485
Mental Health Services Fund	1,129	1,128	-1
Caseloads			
Developmental Centers	1,552	1,304	-248
Regional Centers	256,872	266,100	9,228
Authorized Positions			
Developmental Centers	5,154.0	4,768.0	-386.0
Headquarters	374.5	374.5	0.0

ISSUE ALERT:

SENATE BILL 946

Statewide we are seeing a multitude of issues as families with children diagnosed with autism transition from regional center funded ABA services to funding supported by private health insurance plans, under the authority of Senate Bill 946 (SB 946).

We seek your expertise in solving these problems and offer our assistance to develop meaningful solutions for these impacted families.

Co-Pays & Deductibles

Families across the state are having very different experiences with co-pays and deductibles. This is due in part to regional centers statewide having different approaches to co-pays (assessing who will pay the co-pay and caps on co-pays). Also there are problems with the frequency of co-pays (i.e. per therapy visit vs. per week of therapy visits) and reaching deductibles through the co-pays.

Actions Requested:

- ♦ Define the payment obligations associated with co-pays between health plan subscribers and regional centers.
- ♦ Define the frequency for the payment of a co-pay as associated with ABA programs ranging in 10-40 hour weekly programs (i.e. offer guidance on whether a co-pay is paid with each daily session, per week or per month).
- ♦ Define the payment obligations associated with deductibles between health plan subscribers and regional centers.
- ♦ Ensure that health plan companies are basing deductibles on actual costs and not the schedule of maximum allowances of services rate valuation of services received.

Some regional centers only cover 25% of the co-pay; some will cover the co-pay up to a pre-determined amount.

Whereas, other regional centers will pay 100% of the co-pay but are refusing to cover previously funded services like parent training, clinical supervision and report writing.

Inadequate Networks of Providers

Families across the state are reporting that their health insurance plan has failed to contract with an adequate number of providers in their geographic area to meet the timelines as indicated by the law.

The result is that families experience significant delays: they wait up to 4-6 weeks for an assessment, the assessment takes another 4-6 weeks to get approved by the plan and then maybe within 1-2 weeks after that, services start. In sum, 3 1/2 months (or more) may have transpired before the child actually starts to receive services.

Actions Requested:

- ◆ Define “adequate” for purposes of SB 946 as meaning more than 2 providers in a network.
- ◆ Define “network” for purposes of SB 946 as meaning a large and varied group of providers, adequate to serve each geographic area.

Low Rates of Reimbursement

Families report that their health insurance plan will not panel with their current ABA provider, even if the provider has a long standing relationship with the family and/or community as a reputable provider. Families are forced to either opt for the provider offered by the plan or go “out of network” for the current provider. When families go out of network, they risk yet another battle: Will the provider be able to continue to provide services under the low rate of reimbursement?

Providers report that the plans are using rates that are not “usual/reasonable and customary” for their given area. The result is that the provider either passes the difference between their actual rate and that of the reimbursement rate onto to the family or the provider declines continuing to serve the family, as they cannot work for such low rates.

Actions Requested:

- ◆ Provide guidance on usual/reasonable and customary rates for “qualified autism service providers” as stated in SB 946.

Mary Ellen Stives, Area Board 13 (San Diego and Imperial Counties) 619-688-3323
MaryEllen.Stives@scdd.ca.gov

Anastasia Bacigalupo, Area Board 9 (San Luis Obispo, Santa Barbara, and Ventura Counties)
805-648-0220 Anastasia.Bacigalupo@scdd.ca.org

It's About Ability

An explanation of the Convention on
the Rights of Persons with Disabilities



A World Enabled 
THE VICTOR PINEDA FOUNDATION

unicef 

ACKNOWLEDGEMENTS

The text for this booklet was prepared by Victor Santiago Pineda, founder of the Victor Pineda Foundation and youngest government delegate to the Ad Hoc Committee that drafted the Convention on the Rights of Persons with Disabilities.

This project was initiated at UNICEF and has been led since its inception by Helen Schulte from UNICEF's Child Protection Section, with support from María Cristina Gallegos, Voices of Youth Coordinator in UNICEF's Adolescent Development and Participation Unit. The booklet was edited and produced by UNICEF's Division of Communication.

UNICEF gratefully acknowledges the support of Save the Children UK and Sweden, and the Special Olympics.

We also express appreciation to UNICEF country offices in Armenia, China, Ethiopia, Nicaragua, Thailand and Uzbekistan for their important contributions.

Special thanks go to the children and youth with disabilities who shared their insights at consultations organized by Save the Children and the Arab Human Rights Foundation in Sana'a, Yemen, in October 2007, and at a Youth Summit organized by the Special Olympics in Shanghai, China, parallel to the World Summer Games in October 2007. Many thanks also to those who participated in online consultations through UNICEF's Voices of Youth, and to the young leaders with disabilities from the Victor Pineda Foundation's A World Enabled initiative.

UNICEF is especially indebted to the children who contributed their poems and artwork.

We would also like to thank the members of the project's technical advisory group for their thoughtful comments on successive drafts, in particular, Saudamini Siegrist (UNICEF Florence), Gerison Lansdown (independent consultant), Alexandra Yuster, Daniel Seymour and Nadine Perrault (UNICEF New York), Catherine Naughton (Christian Blind Mission), and Cherie Tropet and Vanessa Anaya (Victor Pineda Foundation), who helped rewrite early drafts.

We gratefully acknowledge the generous support for this project from the German Committee for UNICEF.

© United Nations Children's Fund (UNICEF)
April 2008

Permission to reproduce any part of this publication is required. Please contact the Development Professionals Section, Division of Communication, UNICEF

3 UN Plaza, New York, NY 10017, USA
Tel.: (+1-212) 326-7434
Fax: (+1-212) 303-7985
Email: nyhqdoc.permit@unicef.org

Permission will be freely granted to educational or non-profit organizations. Others will be requested to pay a small fee.

Cover illustration by Lisa Lavoie, inspired by a drawing by Lea Nohemí Hernández

Book design by Christina Bliss

IT'S ABOUT ABILITY

An explanation of the Convention on
the Rights of Persons with Disabilities

CONTENTS



The issue

2



Actions for change

3



About this book

3



About the Convention

7



The Convention on the Rights of Persons with Disabilities in brief

8



How rights become real

17



Test your knowledge

19



Glossary

21

The issue

*I have no legs,
But I still have feelings,
I cannot see,
But I think all the time,
Although I'm deaf,
I still want to communicate,
Why do people see me as useless, thoughtless, talkless,
When I am as capable as any,
For thoughts about our world.*

—Coralie Severs, 14, United Kingdom

This poem speaks for millions of children and adults, living everywhere in the world, who have disabilities. Many face discrimination every day. Their abilities are overlooked and their capacities underestimated. They don't get the education and health care they need, and they are excluded from activities in their community.

But children and adults with disabilities have the same rights as everyone else.



“Encourage me ... you can do it!” Bismark Benavides, 13, Nicaragua

Actions for change

That is why the Convention on the Rights of Persons with Disabilities was created. This international agreement requires that governments around the world uphold the rights of children and adults with disabilities.

UNICEF and its partners are working to encourage all countries to ratify the Convention. This will protect children with disabilities from discrimination and promote their inclusion in society. We all have a role to play. Read on to find out how to get involved in making sure everyone is treated in the way they should be.

Understanding disability

Have you ever felt left out? Children and adults who find it difficult to see, learn, walk or hear often feel excluded. There are many barriers that can prevent them from participating in the same way as others, and most of these barriers are imposed by society. A child in a wheelchair, for example, wants to go to school, too. But he or she may not be able to do so because the school has no ramp and the principal or teachers are not supportive. For everyone to be included, we need to change existing rules, attitudes and even buildings.



About this book

This book was created for and with the participation of children to explain the Convention on the Rights of Persons with Disabilities, why it was created and how it can help people with disabilities realize their rights. We hope you can use the book to help spread the word so that children with disabilities have an equal chance at achieving their goals.

You may have a disability, or you may know someone who does. People with disabilities may have difficulty seeing, hearing, walking or remembering. But they also have dreams, hopes and ideas they want to share – as in the drawings and poems published here.

We encourage you to share this information with your parents, your teachers, your friends and anyone else you think would be interested.

In this book you will find a summary of the Convention on the Rights of Persons with Disabilities and the reasons it was created. You can learn about everyone's rights and responsibilities, and about the steps and actions governments must take to help children with disabilities realize their rights. And you can learn what actions you can take to make a difference.

At the end of the book is a list of words and what they mean. The list, or glossary, will help you understand words that may be new to you.



What is a convention

A convention is an agreement between countries to obey the same law about a specific issue. When a country signs and ratifies (approves) a convention, it becomes a legal promise and guides the actions of the government. It often leads the government to adapt and change its own laws to support the goals of the convention.

What are human rights

Everyone in the world is protected by laws that defend their rights and inherent dignity (the dignity all people are born with). No one is excluded. For example, every human being has a right to life and freedom from slavery. These rights are affirmed in the Universal Declaration of Human Rights, adopted by all member states of the United Nations in 1948. All children have the right to food and health care, the right to go to school and the right to be protected from violence and abuse. Children also have the right to say what they think should happen when adults are making decisions that affect them, and to have their opinions taken into account. The rights of children are stated in the Convention on the Rights of the Child.



The message is ABILITY

by Victor Santiago Pineda, president of the Victor Pineda Foundation

When I was five years old, I stopped walking. As I grew older, my muscles became too weak even to help me breathe. I thought nobody liked me because I was different. My parents did not know what to do. But they always made me feel loved. They believed in me and let me take risks and try new things. I developed self-confidence.

My family knew that I would have to fight to make my own way. Throughout my childhood, I had to change people's ideas of what I could do and how I could do it. Eventually, I found out that there are laws that protect me. Because of these laws, I received the help that I needed and was able to become a great student.

I grew up wondering what my life would have been like had I lived in some place that did not protect the rights of children like me. I discovered that people like me from all over the world were meeting at the United Nations to work on these issues, and I worked hard to join them.

I was the youngest delegate to the special United Nations committee that drafted the Convention on the Rights of Persons with Disabilities. I made many friends and shared my ideas, and together with governments, we created the Convention.

Every person in the world looks different and has different ideas, experiences, traditions and abilities. I learned that these differences create new possibilities, new hopes, new dreams and new friendships.

This book is a call for action, for children with and without disabilities to stand side by side and fight for what's right. The differences among the people of our world are a treasure for all to appreciate and share. Each child is part of the world family and contributes their unique abilities. Every child is included.

Victor Santiago Pineda is an educator and filmmaker who works with young people who have disabilities to inform them of their rights. He developed the A World Enabled initiative with his Foundation to educate the public about the abilities and potential of young people with disabilities. Mr. Pineda has worked with the United Nations, the World Bank and government leaders to promote respect, equal opportunities and dignity for everyone. He has muscular dystrophy and uses a wheelchair to get around.

Having a disability is not a bad thing. It can even be something to be proud of. We are all different and all have different **ABILITIES**. Every child can be an ambassador of ability to our families, schools and communities. We each have ideas, experiences and skills that can serve everybody else. This book calls on all people from all nations to honour and respect us just the way we are.

– Victor Santiago Pineda

*I am happy when...
 I am happy with small things
 I am happy when...
 People understand what I am trying to say
 When I talk with other people on the same level
 I am happy because I am proud of myself
 I am happy when I study
 By studying I can learn new information
 I get to understand the news from all over the world
 I can calculate how much to pay when I am eating
 I can say what I think is right or wrong
 I am happy because I get to do so many things by myself
 I am happy because I have a favorite thing to do
 I am happy when I am cheering for soccer players
 Because their passion is so great
 I feel as if I am one of them
 And I also get very passionate
 I am happy because I have a dream
 It may seem small but
 Planning and living faithfully every day
 Makes me feel so happy*

—Kim Yoona, 15, Republic of Korea



"Right to play," Javlon Rakmonberdiev, 12, Uzbekistan

About the Convention

The Convention on the Rights of Persons with Disabilities is an agreement by countries around the world to make sure that people with disabilities and people without disabilities are treated equally. Conventions, sometimes called treaties, covenants, international agreements or legal instruments, tell your government what to do to make sure you can enjoy your rights. All adults and children with disabilities, girls and boys alike, are included.

The Convention on the Rights of Persons with Disabilities was adopted on 13 December 2006. By 2 April 2008, 20 countries had ratified the Convention, which means that it will enter into force on 3 May 2008 (see the rules of the Convention at www.un.org/disabilities).

Although the Convention is for all persons with disabilities, regardless of age, this book looks at what the rights mean in the lives of children, because you are important!

Why care about the Convention?

If you, your parents or others in your family have a disability, this Convention offers useful information and encouragement. It guides you and your family—and friends who want to help you—in exercising your rights. It also defines the actions governments must take to help all people with disabilities realize their rights.

People with different disabilities from many different countries worked together with their governments to develop this Convention. They got ideas by looking at good actions and laws that were helping people with disabilities go to school, get a job, have fun and live happily in their communities.

Many existing rules, attitudes and even buildings need to be changed to make sure a child with a disability can go to school, play and take part in things every child wants to do. If your government ratified the Convention, it agreed to make these changes happen.

It is important to remember that the rights in this Convention are not new rights. They are the same human rights recognized in the Universal Declaration of Human Rights, the Convention on the Rights of the Child and other international human rights treaties. The Convention on the Rights of Persons with Disabilities guarantees that these rights are respected for people with disabilities.

*Optimism is our motto in life
Listen my friend, my friends
Let your motto be love and faith
Life is a gift from our merciful Lord
To all creatures in heaven as on earth
If you have friends with disability
Stay close to them to help them feel secure
Urge them to be optimistic and to love life
Tell them that despair is cowardice
And that perseverance and determination are signs
of courage
Hope is our aim in life
A gentle smile brings us together
There is no despair in life and no life in despair*

—Jwan Jihad Medhat, 13, Iraq

The Convention on the Rights of Persons with Disabilities in brief

The Convention makes many promises. Its 50 articles clearly explain what these promises are. Where we say 'government' in the following pages, we mean the governments that have ratified the Convention (also called 'States parties').



What are laws

Laws are rules that everyone has to follow so that people respect each other and live together safely.

What does it mean to ratify

Governments that ratify a Convention agree to do their best to enforce its articles. Check to see if your country has ratified the Convention. If it has, then you can remind your government representatives of their responsibilities. The United Nations publishes a list of States parties that have signed and agreed to the Convention. To see online if your country has ratified the Convention, look at the United Nations website: <www.un.org/disabilities>.



Article 1: **Purpose**

This article summarizes the Convention's main objective, which is to promote, protect and ensure the full and equal enjoyment of all human rights and freedoms by all people with disabilities, including children.

Article 2: **Definitions**

This article lists words that have a particular definition in this Convention. For example, "language" includes spoken words and also signed or other non-spoken languages. "Communication" includes languages, text displays, Braille (which uses raised dots for letters and numbers), communication through touch, large print and accessible multimedia (such as websites or audio).

Article 3: **General principles**

The principles (main beliefs) of this Convention are:

- (a) Respect for everyone's inherent dignity, freedom to make their own choices and independence.
- (b) Non-discrimination (treating everyone fairly).
- (c) Full participation and inclusion in society (being included in your community).
- (d) Respect for differences and accepting people with disabilities as part of human diversity.
- (e) Equal opportunity.
- (f) Accessibility (having access to transportation, places and information, and not being refused access because you have a disability).
- (g) Equality between men and women (having the same opportunities whether you are a girl or a boy).
- (h) Respect for the evolving capacity of children with disabilities and their right to preserve their identity (being respected for your abilities and proud of who you are).

Article 4: **General obligations**

There should be no laws that discriminate against people with disabilities. If necessary, governments should create new laws to protect the rights of persons with disabilities and put these laws into action. If old laws or traditions discriminate against people with disabilities, governments should find ways to change them.



If there are laws or practices that prevent children with disabilities from doing the same things as other children, they must be changed. Your government should consult with organizations of children with disabilities as it changes such laws and policies.

THE CONVENTION IN BRIEF

To develop new laws and policies, governments should seek advice from people with disabilities, including children.

Article 5: **Equality and non-discrimination**

Governments recognize that all people have the right to be protected by the law, and that the laws of a country apply to everyone who lives there.

Article 6: **Women with disabilities**

Governments know that women and girls with disabilities face many different types of discrimination. They agree to protect their human rights and freedoms.

Article 7: **Children with disabilities**

Governments agree to take every possible action so that children with disabilities can enjoy all human rights and freedoms equally with other children. They also agree to make sure that children with disabilities can express their views freely on all things that affect them. What is best for each child should always be considered first.

Boys and girls with disabilities have the same rights as all children. For example, every child has the right to go to school, to play and be protected from violence, and to be involved in decisions that affect him or her. Governments must provide the information and support necessary for children with disabilities to realize this right.

Article 8: **Awareness raising**

Governments should educate everyone about the rights and dignity of persons with disabilities and their achievements and skills. They agree to combat stereotypes, prejudice and activities that might harm people with disabilities. Your school, for example, should promote an attitude of respect towards people with disabilities, even among very young children.

Article 9: **Accessibility**

Governments agree to make it possible for people with disabilities to live independently and participate in their communities. Any place that is open to the public, including buildings, roads, schools and hospitals, must be accessible by persons with disabilities, including children. If you are in a public building and need help, a guide, reader or professional sign language interpreter should be there to assist you.

The media should report on unfairness towards children and adults with disabilities.



Lisa Laviole



"Peace for every child," Ani Verdyan, 8, Armenia



What about technology

Telephones, computers and other technology should be easy to use for people with different abilities. For example, websites can be designed so that people who have difficulty using keyboards, seeing or hearing can enjoy the information in a different format. A computer can have a Braille keyboard, or it can use a speech synthesizer to speak words that appear on the screen.

THE CONVENTION IN BRIEF

Article 10: **Right to life**

Every human being is born with the right to life. Governments guarantee that this is equally true for people with and without disabilities.

Article 11: **Situations of risk and emergencies**

People with disabilities have the same right as everyone else to be protected and safe during a war, an emergency or a natural disaster, such as a storm. You cannot legally be excluded from a shelter or left alone while others are rescued because you have a disability.

You have the right to life. It is your gift, and no one, by law, can take it from you.



Article 12: **Equal recognition before the law**

People with disabilities have the right to enjoy 'legal capacity' in the same way as other people. This means that, when you grow up, whether or not you have a disability, you can do things like get a loan to study or sign a lease to rent your own apartment. And you can own or inherit property.

Article 13: **Access to justice**

If you are harmed by a crime, have seen others harmed or are accused of doing something wrong, you have the right to be treated fairly when your case is being investigated and dealt with. You must be given help to express yourself in all legal processes.

Article 14: **Liberty and security of the person**

Governments should make sure that people with disabilities have their freedom protected by law, the same as all other people.

Article 15: **Freedom from torture or cruel, inhuman or degrading treatment or punishment**

No one should be tortured or humiliated or treated cruelly. And everyone has the right to refuse medical or scientific experiments.

Article 16: **Freedom from violence and abuse**

Children with disabilities should be protected from violence and abuse. They should not be mistreated or harmed in their home or outside. If you have faced violence or maltreatment, you have the right to get help to stop the abuse and recover.

Article 17: **Protecting the person**

No one can treat you as less of a person because of your physical and mental abilities. You have the right to be respected by others just as you are!

Article 18: Liberty of movement and nationality

Every child has the right to a legally registered name, a nationality and, as far as possible, the right to know and be cared for by his or her parents. And people cannot be stopped from entering or leaving a country because they have disabilities.

Article 19: Living independently and being included in the community

People have the right to make choices about where they live, whether or not they have a disability. When you grow up, you will have the right to live independently if you prefer and to be included in your community. You must also have access to support services if you need help to live in the community, such as care in your home and personal assistance.

Article 20: Personal mobility

Children with disabilities have the right to move about and be independent. Governments must help them do so.

Article 21: Freedom of expression and opinion, and access to information

People have the right to express their opinions, to seek, receive and share information and to receive information in forms that they can understand and use.

Article 22: Respect for privacy

Nobody can interfere in people's private affairs, whether they have disabilities or not. People who know information about others, such as their health status, should keep this information private.

Article 23: Respect for home and the family

People have the right to live with their families. If you have a disability, your government should support your family with disability-related expenses, information and services. You should not be separated from your parents because you have a disability! If you cannot live with your immediate family, the government should help provide care within the wider family or community. Young people with disabilities have the same rights as other young people to reproductive health information and the same rights as others to marry and start a family.



Children with disabilities have the right to move about and be independent.

Lisa Laviole

THE CONVENTION IN BRIEF



"Daily life in my community," Pedro José Rivera, 14, Nicaragua

Article 24 **Education**

People have the right to go to school. If you have a disability, you cannot be excluded from education because of it. You should not be educated in segregated schools. You have the right to the same education and curriculum as other children, and your government must give you the help you need to make this happen. For example, it must provide suitable ways for you to communicate so that your teachers understand how to respond to your needs.

Articles 25 and 26 **Health and rehabilitation**

People with disabilities have the right to the same range and quality of free or affordable health care as provided to other people. If you have a disability, you also have the right to health and rehabilitation services.

Article 27 **Work and employment**

People with disabilities have an equal right to work at a freely chosen job without discrimination.

Article 28: Adequate standard of living and social protection

People with disabilities have a right to food, clean water, clothing and access to housing, without discrimination. The government should help children with disabilities who live in poverty.

Article 29: Participation in political and public life

People with disabilities have the right to take part in politics and public life. Once you reach the age set by the laws of your country, you have the right to form a group, serve the public, access voting booths, vote and be elected to a government position, whether you have a disability or not.

Article 30: Participation in cultural life, recreation, leisure and sport

People with disabilities have the same right as others to participate in and enjoy the arts, sports, games, films and other fun activities. So, theatres, museums, playgrounds and libraries should be accessible by everyone, including children with disabilities.

Article 31: Statistics and data collection

Countries must collect data about disabilities to develop better programmes and services. Persons with disabilities who contribute to research on disability have the right to be treated in a respectful and humane way. Any private information they share must be kept confidential. The statistics collected must be made accessible to persons with disabilities and others.

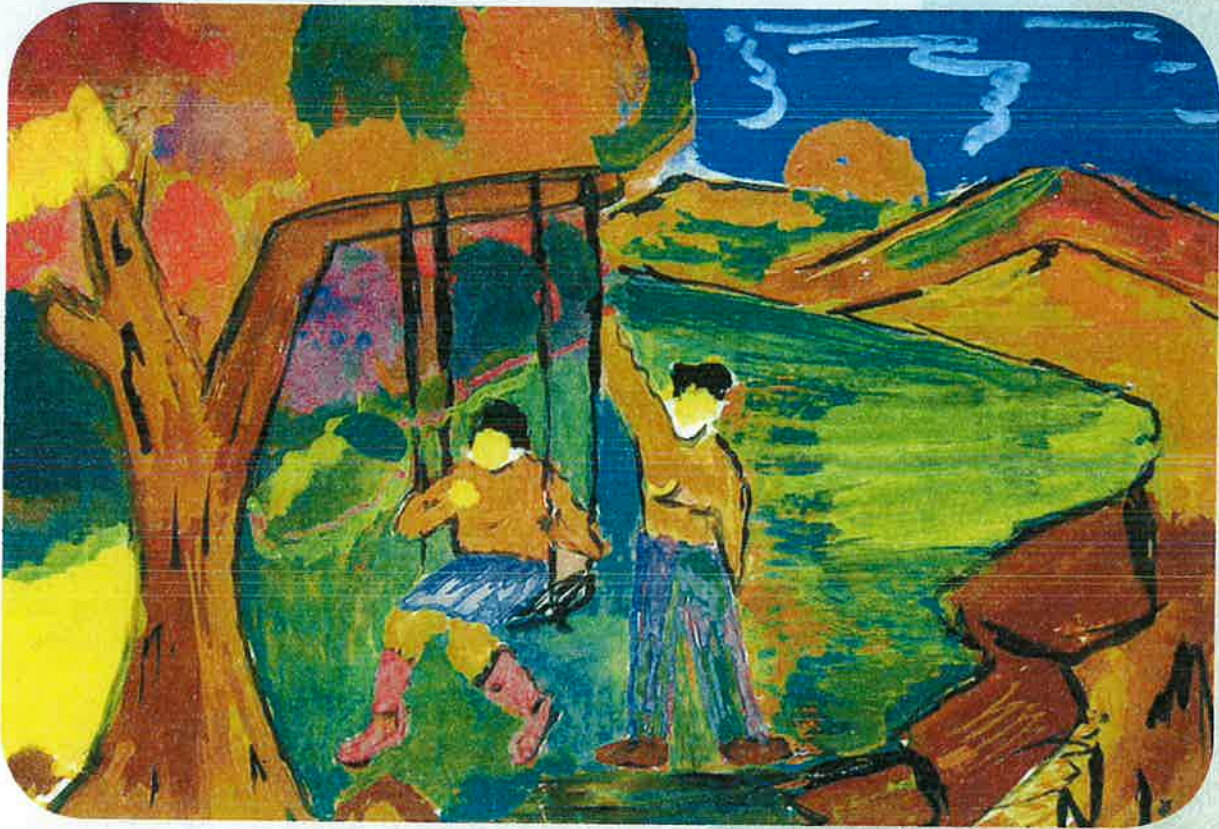
Article 32: International cooperation

Countries should help each other fulfil the articles of this convention. This includes countries with more resources (such as scientific information, useful technology) sharing with other countries, so that more people in the world can enjoy the rights of the convention.

Articles 33 to 50: Rules on cooperation, monitoring and implementation of the Convention

The Convention on the Rights of Persons with Disabilities has 50 articles in all. Articles 33 to 50 are about how adults, especially people with disabilities and their organizations, and governments should work together to make sure all persons with disabilities get all their rights. See the text of these articles at www.un.org/disabilities.





"We are playing," Tatev Danielyan, 15, Armenia

*Two Worlds...
 Torn between the ears of
 Sounds and Silent,
 Uncertain, unable to join...
 Tears flow...
 Unknowingly both push away,
 Rejected, made to feel
 Unbelonging...
 Tears flow...
 'Cept certain hands,
 Pulls, pushes, encourages,
 Is Relentless...
 Tears flow, a smile growing...
 Still stuck between,
 But Loved...*

**—Sarah Leslie, 16,
 United States of America**

How rights become real

The rights of children with disabilities are the same as those of all children. It is up to you to let the world know about the Convention. People must speak out and take action if they want their societies to include everyone.

If you have a disability, this Convention gives you, your government and your family tools for achieving your rights and your dreams. You should have an equal chance to go to school and join in other activities. The adults in your life should help you move around, communicate and play with other children, no matter what kind of disability you may have.

You are a citizen, a member of your family and community, and you have a great contribution to make.

What you can do

It's important to change attitudes and rules so that children who have disabilities can go to school, play and take part in activities that every child wants to do. Does your school include children with disabilities in classes and all other activities? Are your teachers listening and responding to those among you who have special needs? Is there a ramp, a sign language interpreter or other assistive technologies? Good! Then your school treats children with disabilities fairly by giving them an equal chance to learn. Your school follows the Convention.

Unfortunately, many people don't treat children with disabilities fairly. You have a role in making your community more inclusive. You can start in your own home and school to change the minds of your parents and teachers.

There are many things you can do to teach others about the Convention on the Rights of Persons with Disabilities and the potential of young people with disabilities. For example, you can:

- 🌱 Get involved with an organization or a campaign. There is strength in numbers. To join forces with others, you can support or join a local chapter of a national or international organization. They may have specific programmes or campaigns for young people.
- 🌱 Create your own project. Start an awareness campaign, hold a fund-raiser, conduct a survey (Has somebody you know been treated unfairly? Does your school have only stairs and no ramps?), write a petition to remove barriers you have encountered.
- 🌱 Organize a club to promote the Convention. Bring children with different abilities together, hold social events with all your friends and invite new people to join. Have movie parties or make dinner together. Just have fun and enjoy each other's unique gifts and abilities.

Stand up for your rights and others will stand by your side. All children **CAN** go to school, **CAN** play and **CAN** take part in everything. It's not about I can't, it's about **I CAN!**

— Victor Santiago Pineda

- Hold presentations in your school and in surrounding schools about the rights of people with disabilities. Be creative. Make posters and put on plays to help your fellow students understand the rights included in the Convention. Ask a parent or teacher to help organize the presentation, and plan where and when you will be able to teach. Invite your school principal to attend your presentations.
- Make art with a group of your friends about the rights of people with disabilities. These can be drawings, paintings or sculptures – whatever you want to make to help share the news. See if you can display your artwork in your school, local libraries, galleries or restaurants – anywhere people will be able to enjoy your art. You can move your exhibition to different locations over time and share the Convention with many people.
- Share your experiences and the lessons you've learned with others. UNICEF's Voices of Youth <www.unicef.org/voy> is a popular online discussion forum for young people.

These are just a few ideas of things you can do – the sky is the limit. Ask a trusted adult to help you organize your activity, and have fun!



"Rock band of children with disabilities," Valeria D'Avola, 13, Italy

For a set of teaching materials, see the forthcoming companion to this booklet titled *It's About Ability: Activities for learning and taking action on the Convention on the Rights of Persons with Disabilities*.

Test your knowledge

(1) Fill in the missing word.

- a. One of the principles of the Convention on the Rights of Persons with Disabilities is full participation and _____ in society.
- b. Many existing rules, attitudes and buildings need to be _____ to make sure a child with a disability can go to school, play and take part in things every child wants to do.
- c. Every person has _____ rights.
- d. Laws should not _____ against people with disabilities.
- e. _____ comes in many forms; it can be written, spoken or signed.

(2) Unscramble the words and form a sentence with them.

ew _____ rea _____ lal _____
dan _____ entffdeir _____ lla _____
vhea _____ biiialtes _____ deeifrntf _____
adn _____ aehv _____ lla _____
ew _____ het _____ ightrs _____
easm _____

(3) What do these children have in common?



Answers:
(1) a. inclusion; b. changed; c. equal; d. discriminate; e. Language
(2) We are all different and all have different abilities, and we all have the same rights.
(3) They all have equal rights.

GLOSSARY

Adopt: Formally approve or accept (for example, a convention or a declaration).

Articles: A paragraph or a section in a legal document that is numbered; these numbers make it easy to find information, and to write and talk about it.

Assistive technologies: Tools that help you do things you otherwise could not do, for example, a wheelchair to help you get around or larger print on a computer screen to help you see.

Committee: A group of people who are chosen to work together and help a larger group of people.

Communication: Sharing information. It also means a way to read, speak or understand information using multimedia, large print, Braille, sign language or having someone read out loud.

Community: A group of people who live in the same area. It also means people with the same interests or concerns.

Convention: A treaty or agreement by a group of countries to develop and follow the same laws.

The Convention on the Rights of the Child is an agreement to ensure that all children can enjoy their rights as members of society and have the special care and protection they need as children. It is the most widely accepted human rights treaty in history.

The Convention on the Rights of Persons with Disabilities is an agreement to ensure that all people, including children with disabilities, can enjoy their rights.

Dignity: Your inherent worthiness and respectability as a human being. Your own self-respect. To be treated with dignity means to be treated with respect by other people.

Discrimination: Unfair treatment of a person or group for any reason: race, religion, gender or different abilities.

Implementation: To put something into effect. Implementing the articles of the Convention means making its promises a reality.

Inherent dignity: The dignity all people are born with.

Legal: Relating to, based on or required by the law.

Muscular dystrophy: A medical condition that causes the muscles to get weaker over time.

Ratification (ratify): When a signed convention or agreement is officially approved by a country and becomes the law in that country.

States parties: Countries that signed and agreed to the Convention.

UNICEF: The United Nations Children's Fund. It is the agency of the United Nations system that works for children's rights, their survival, development and protection, in order to make the world a better, safer and friendlier place for children – and for all of us.

United Nations: An organization of virtually every country in the world. Governments meet at the United Nations in New York and work together for peace and a better world.

Universal Declaration of Human Rights: Signed on 10 December 1948 by all the member countries of the United Nations, this agreement lists the rights of all people.

For every child
Health, Education, Equality, Protection
ADVANCE HUMANITY

For further information, please contact:
Child Protection Section
Programme Division, UNICEF

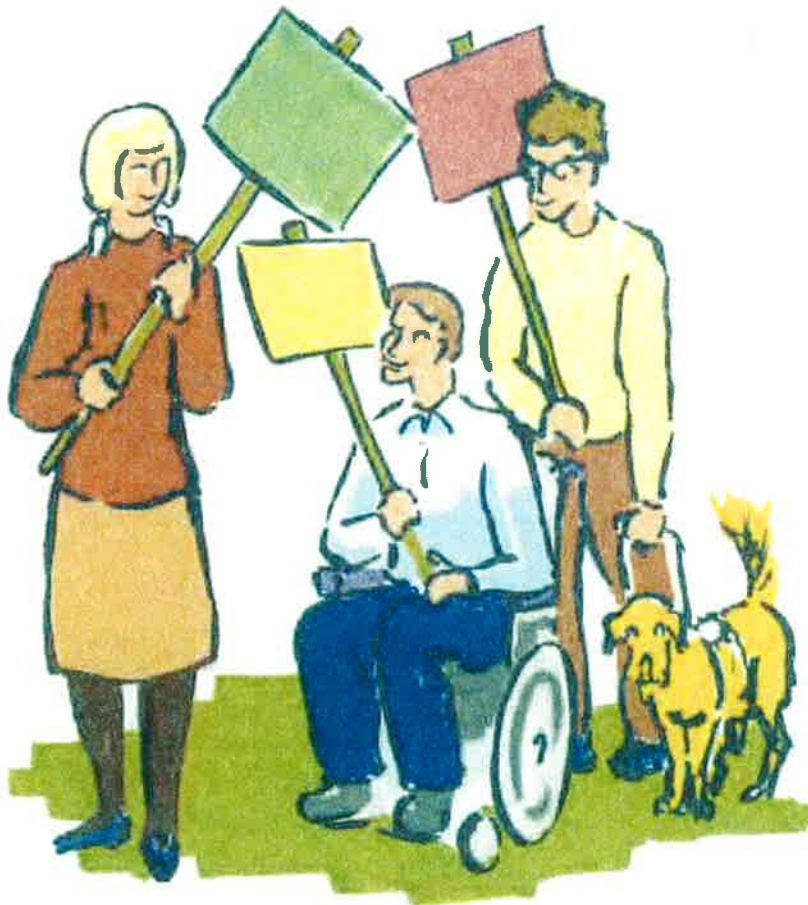
United Nations Children's Fund
3 United Nations Plaza
New York, NY 10017, USA
pubdoc@unicef.org
www.unicef.org

ISBN: 978-92-806-4301-5

© United Nations Children's Fund (UNICEF)
April 2008

unicef 
unite for children

International agreement on the rights of disabled people



Easyread version



The full name of this agreement is the United Nation Convention on the Rights of Persons with Disabilities. In the United Kingdom we say disabled people rather than people with disabilities so you may see or hear it called the United Nations Convention on Disability Rights



There is a list of what is in this paper at the end of this paper on page 51



1. This agreement

This agreement looks at what countries can do to make sure that disabled people have the same rights as everybody else.

2. What the words mean



- **Communication** means the ways that help disabled people to talk and understand information, for example computers, easy read or Braille.



- **Discrimination** being treated unfairly or not getting the changes you need because you are disabled.



- **Language** means any way people talk to each other including sign language.

3. The basic ideas

These are:



- People are free to make their own choices.



- No one will be discriminated against.



- Disabled people have the same rights to be included in society as anybody else.



- Disabled people are to be respected for who they are.



- Everyone should have equal opportunities.



- Everyone should have equal access.



- Men and women should have equal opportunities.

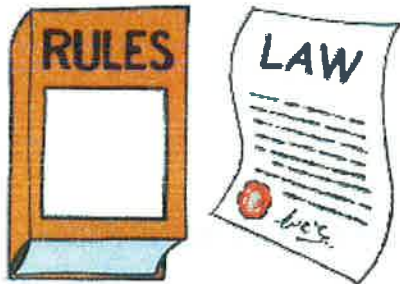


- Disabled children should be respected for who they are as they grow up



4. What countries should do

All countries should make sure that disabled people actually do get treated equally.



They agree to do this by:

- Making new rules and laws to give disabled people their rights and change any bad ones.



- Making sure the rights of disabled people to be treated equally are included in the law.



- Including disability issues in all policies.



- Not doing things that are against this agreement



- Making sure governments and authorities do the things in this agreement.

- Doing as much as they can to make sure no one discriminates against disabled people.



- Making sure things are designed for everyone to use or that can be easily changed.



- Using new technology to help disabled people.



- Giving accessible information to disabled people about the things that will help them.



- Training people about this agreement.



All countries should do as much as they can afford to make sure disabled people are not discriminated against.



All countries should involve disabled people in making new laws and policies.

5. Being equal



Countries agree that everyone is equal under the law and that discrimination against disabled people will not be allowed.

6. Women with disabilities being treated equally



Countries agree that women and girls who are disabled are treated unfairly in lots of different ways.



Countries will work to make sure that disabled women and girls have full, free and equal lives.

7. Children with disabilities being treated equally



Countries agree that disabled children have the same rights and freedom as other children and are treated equally with others.

What is best for the child will be the most important thing to think about.



Countries agree that disabled children have the right to be heard in all things that can affect them in their lives. Support will be given to children to help make this happen.

8. Giving people information about disability



Countries should help people realise the equal rights of disabled people and show what disabled people can do.

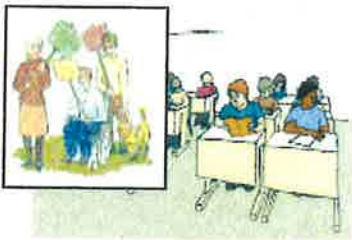
They should do this by:

- Having campaigns to change the way some people think about disabled people's lives and things like getting married or having sex.





- Showing what jobs disabled people can do.



- Teaching all children about equal rights for disabled people.



- Getting the media to show disabled people properly.



- Supporting more disability awareness work.

9. Accessibility

Countries should make sure disabled people have better access to things in all areas of life.



- There should be better access to public buildings like hospitals and schools, and transport

- Signs should be in easy read and Braille.



- More guides and sign language interpreters should be available in public buildings.



- There should be guidelines about how to make access to public services better.



- Accessibility training should be given.



- They should make sure that disabled people have access to new technology.



- They should make sure information is made accessible from the beginning.



- They should make sure that disabled people get the right support to information.

10. Right to life

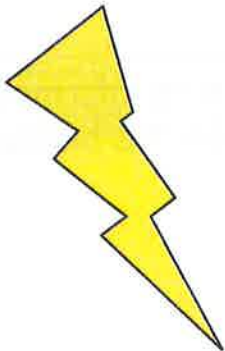


Everyone has the right to life including disabled people.



Countries should make sure disabled people have the same chances as anyone else to live their lives.

11. Emergencies



Making sure that disabled people are properly protected when there are risky situations for everyone, for example when hurricanes happen.

12. Being treated equally by the law



Disabled people are to be respected as people like everyone else.



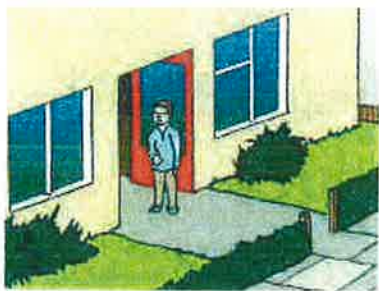
Disabled people have the same right to make their own decisions about important things as everyone else.

Disabled people should have the proper support they need when making decisions.



If a person really does need someone else to speak for them there should be rules to make sure this is done properly.

Disabled people have equal rights to:



- Own or be given property.



- Control their own money.



- Be able to borrow money the same as anyone else.



- Not have their homes or money taken away from them.

13. Getting justice



Disabled people should have the same rights to go to court, take other people to court or take part in what happens in courts as anyone else.



Disabled people should get support to make sure they get these rights.



Countries should have special training for courts, police and prison staff.

14. Being free and safe



Disabled people should be free and safe, the same as everyone else.



Disabled people should not be locked up just because they are disabled but only if the law says so for other reasons.

If disabled people are locked up they should be treated with respect and in the ways this agreement says.



They should also have the same rights that everyone else has under other international laws. This agreement does not list those rights but they include being:



- Given accessible information about their rights.



- Given access to help and support to get a fair hearing in a court.



- Having their case reviewed as often as other people would.

15. Not being tortured or treated cruelly



Disabled people must not be treated cruelly or tortured.



Disabled people must not be experimented on, especially medical experiments, (unless they freely agree).



Countries must do everything possible to make sure these things do not happen.

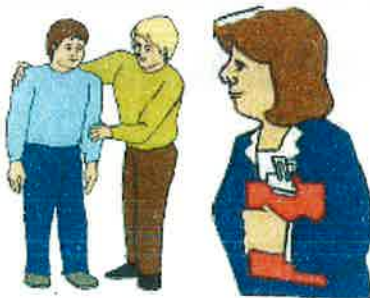
16. Not being used or abused



Countries must make laws and rules to make sure disabled people are protected in the home and outside from violence, being used or abused.



Countries must also try to prevent abuse and they should make sure there is proper support, information and training on how to see abuse and how to report it.



Countries should make sure that services that support disabled people are properly checked up on to make sure abuse does not happen.



Countries should make sure that disabled people who have been abused should be given the help and support they need to keep them safe and help recover from the abuse.



Countries must make sure they have good ways of finding out about abuse and making the abusers go to court.



Countries must think especially about the abuse of women and children.

17. Treating disabled people as people first



Disabled people should be treated like anyone else, with the same respect and rights as others.

18. Moving around



Disabled people have the right:

- To decide where they live and to move about the same as every one else.



- To belong to a country (be a citizen) and not have that taken away because they are disabled.

- To have papers, like passports, that other people have.



- To leave any country including their own.



- Disabled children will have the right to a name from birth, a right to be a citizen and if possible, the right to know and be cared for by their parents.



19. Independent living and being a part of the Community



Countries should make sure disabled people have freedom of choice, independent living and to be a part of their communities.



Disabled people can choose:

- Where they live, the same as everyone else.



- Who they live with, the same as everyone else.



- And not to live in a particular place like a hostel if they don't want to.



- From a range of different support services including personal assistance.



- From the same range of services that other people can choose from and get a good service.



20. Getting about

Countries should make sure disabled people can get about independently as much as possible.

They should:



- Help people get about.



- Help people get good aids and help to get about.



- Make sure these things don't cost too much.



- Give training on how to get about.



- Get companies that make aids to think about all different needs of disabled people.

21. Saying what you want and access to information



Countries must make sure that disabled people have the right to find out and give information and to say what they want, the same as everyone else.

This includes:



- Information in the way you need it, easy read for example.



- Providing sign languages, Braille and other ways of information.



- Telling other services to do accessible information.



- Getting the media, including the Internet to provide accessible information.

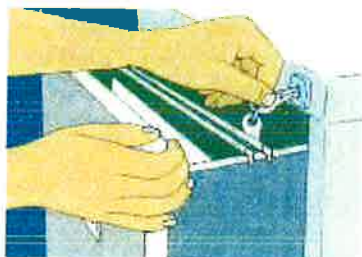


- Supporting the use of sign language.

22. Privacy



Disabled people have the right to a private life and no one should interfere with or get in the way of that.



Countries must make sure that personal information about disabled people is kept confidential or private the same as everyone else's.

23. Respect for the home and the family



Countries must make sure that disabled people have equal rights to marriage, a family and personal relationships.

Countries must make sure that:



- Disabled people have equal rights to get married and start a family as long as both of the couple want to.



- Disabled people have a right to decide how many children they have and when to have them, and not be sterilised against their will.



- Disabled people have the right to family planning and other information to help them decide these things.



- Countries will provide support to disabled people to help bring up their children.



- Children with disabilities have the right not to be kept apart from their families. Countries must support disabled children and their families.



- The rights of children come first.

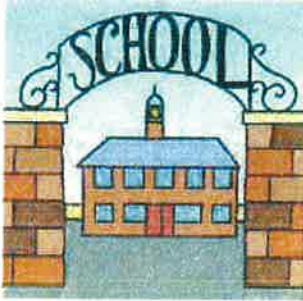


- Countries will make sure children are not taken away from their parents if they don't want to be, except when the law says it is in the best interests of the child. This will not happen because of disability.

24. Education



Disabled people have a right to education.



Countries will make sure disabled people have the opportunity to go to mainstream schools and can carry on learning throughout their lives so that:



- People can learn or do as much as they are able to or want to.



- Disabled people are not excluded from (kept out of) any sort of education.



- Disabled people can go to good local schools, and don't have to pay for them, the same as everyone else.



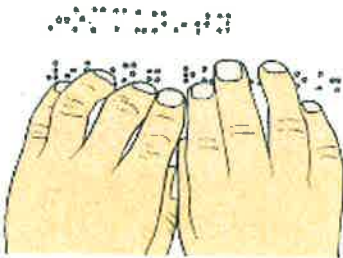
- Disabled people have their needs met as far as possible.



- If needs can not be met in a mainstream school other education can be given as long as it doesn't leave people out from society.



- Training for teachers and staff to support disabled people properly.



- Teach people to learn Braille and other ways of communicating as needed.



- Teach people sign language and see it as a language of the deaf community.



- Make sure deaf and blind children get the right education and support for them to learn.



- Make sure teachers have the right skills.



- Provide the right support for disabled people to continue their education as adults if they want to.

25. Health



Disabled people have the right to good health and access to health services.

Countries will:



- Make sure disabled people have access to the same health services as others.
- Make sure disabled people get the health services they need because of their disability.



- Make sure services are near to where people live.



- Make sure health professionals give the same service to disabled people as to others.



- Make sure disabled people are not discriminated against in health and life insurance.
- Make sure people are not refused care or treatment because they are disabled.

26. Services to help you recover



Countries will make sure disabled people can lead an independent and healthy a life as possible and will provide support in health, work, education and social services to help that happen.



- Countries will make sure that they look at disabled peoples' needs and strengths at an early stage so that disabled people get the support and services they need.



- These services will be as near to where disabled people live as possible.



- Staff will be trained to do a good job.



- Countries will look at the different aids and equipment made to support disabled people to recover.



27. Work

Disabled people have a right to work, equal with others.

Countries will do more to get disabled people work and will help do this by:



- Making laws that make sure disabled people are treated equally and fairly at work.



- Making sure disabled people have equal job rights and rules and pay.



- Making sure disabled people have a right to join a union in line with the laws of the country.



- Making sure disabled people can go on work programmes and work training.



- Helping disabled people find and keep jobs as well as get better jobs.



- Helping disabled people set up their own businesses.



- Giving disabled workers jobs with Government and in places like councils and hospitals.



- Helping companies give disabled people jobs.



- Making sure disabled people have suitable places to work.



- Making sure disabled people can try out work.

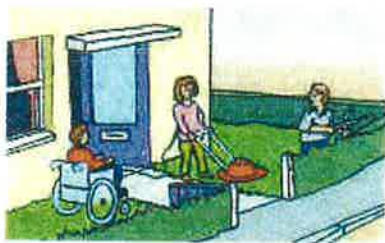


- Help disabled people get back to work.



- Countries must make sure that disabled people are not forced to do unpaid work.

28. Standards of living



Disabled people have an equal right to a good enough standard of living for them and their families. This includes food, clothing, housing and clean water.

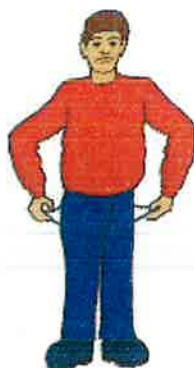
Disabled people should be able to get help to improve their standard of living the same as everyone else.



- Disabled people should have the right services and aids for their disability, at a price they can afford.



- Disabled people especially girls and women and older people, should have help to have a good enough standard of living.



- Make sure disabled people who are poor get help from the state with the costs of disability.



- Make sure disabled people can get public housing.



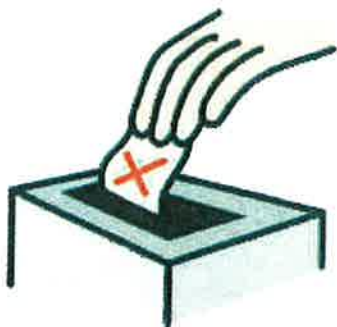
- Make sure that disabled people have the same chances to get retirement pensions as other people.



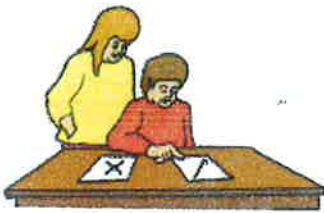
29. Being involved in politics

Disabled people have the right to take part in politics the same as every one else.

Disabled people have the right to vote by:



- Making sure voting is easy to do and understand.
- Making sure voting is secret.



- Allowing support to help people vote in the way they want, when needed.



- Making sure disabled people can be involved in non government organisations and political parties.



- Making sure disabled people can join organisations of disabled people. Disabled people have the right to stand for election as MPs and councillors.



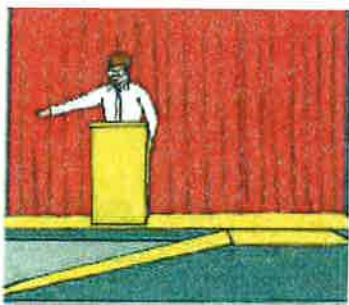
30. Sport and leisure

Disabled people have the right to take part in sports and leisure as much as anybody else.

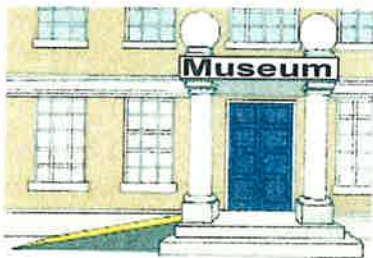


Countries should work towards making sure that:

- Things like books are accessible.



- Television, films and theatres are accessible.



- Disabled people can get into places like museums.



- Disabled people have the opportunity to be artists in their own right.



- Rules and laws should not make it more difficult for disabled people to do these things.



- Deaf and other cultures are respected.



- Disabled people are supported to take part in ordinary sports.



- Disabled people are able to take part in disability sports and leisure activities.



- Sports places are accessible.

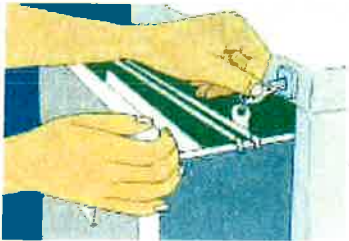


- Disabled children have equal access as well.

31. Information



Countries should collect the information they need to help make this agreement happen.



Information must be kept confidential and private.

32. Countries working Together

Countries will work together as partners to make this agreement happen.

They should:



- Make sure that working together includes disabled people.



- Make sure that countries share information, experiences and training so that all people work in the best way.



- Make sure that countries work together on research and share what they find out.

33. Making this agreement happen



Governments should:

- Have one area of Government dealing with making this agreement happen.



- Have a way that measures how well the agreement is happening.



- Involve disabled people in looking at how well this happens.

34. Committee on the rights of disabled people



A Committee will be made to support the rights of disabled people. This will be made up of 12 experts at first and then 18 people later on.



- The members of the Committee will be part of the group for 4 years. They will not speak up for an organisation.



However, 6 members from the first group will only be part of the group for 2 years.



- Members will be voted in by the countries involved in this agreement. They will look at where different members come from, what their skills are. They will welcome experts who are disabled.



- Elections will take place by a secret ballot or voting at the big meeting about this work. The person with the most votes will be elected onto the Committee.



- The election will take place no later than 6 months after that date that this agreement starts. Countries will have 2 months notice to send in ideas for people to be on the Committee to the Secretary General.

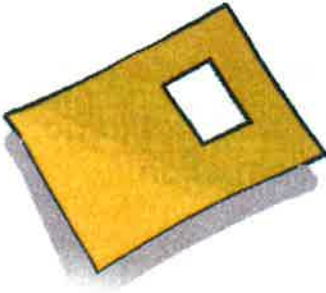


- The Committee will make its own rules about how it will work.



The Secretary General of the United Nations will make sure that the Committee have support from staff and the things they need to do their job.

35. Reports from Countries involved



Each country will write a report about their work for this agreement and send it to the Committee within 2 years after they agree to join.



- After that, each country will send a report every 4 years, as well as extra reports if the Committee asks for them.



- The Committee will decide what information countries need to put in their reports.



- The reports can also be about things that are holding up disabled people's rights.

36. What happens to the reports



The Committee will look at the reports and give countries ideas and advice about what to do. They can also ask for more information.



- If the report is very late, the Committee can warn the country that in 3 months time it will go ahead and look at what is happening there anyway.



- All Countries will be able to see all reports.



- Each Country must make sure that the public can see its report and what the Committee has said about it.



- The Committee will send the reports to different departments and organisations to ask for advice or help if needed.

37. The Committee and Countries working together



Each Country will work together with the Committee and help the Committee members with any information that they need.



The Committee will think about how it can work with Countries to make this work happen in a good way.

38. How the Committee will work with other organisations



It is important that all countries and organisations work together to make this work happen.



- Different departments and organisations will be invited by the Committee to give advice and information about their area of work.



- The Committee may ask other human rights organisations to write reports about how their work fits into this agreement.

39. The Committee Report



The Committee will write a report every 2 years for the General Assembly and the Economic and Social Council. It will include ideas from the different countries about what should be done.

40. Meetings for the Countries involved



Countries involved will meet often to think about the work of this agreement.



The first meeting will be no later than 6 months from the start of this work. The Secretary General will decide on future meetings.

41. Keeping hold of all the reports and information



The Secretary General of the United Nations will hold all the information and reports for this work.



42. Signing the Agreement

Countries will be able to sign this agreement from the 30th of March 2007 at the United Nations Headquarters in New York.

43. Consent and Approval



The agreement starts in countries that have signed it only when they properly agree to it later on.

Other countries who have not signed it can join it too.

44. Groups of Countries



Some countries are joined together in organisations, like the European Union.



These organisations can also join the agreement and also have a say when countries meet to talk about the agreement.

45. When will the agreement start?



The agreement will start 30 days after 20 countries have approved it.



46. Keeping to the agreement

Countries can say if there are parts of the agreement that they do not agree to, but they cannot say that about anything that is a main part of the agreement.



47. Amendments and changes to the Agreement

Any Country can ask for changes to the agreement. They can do this by writing to the Secretary General who will tell the other Countries.

The Countries will decide if they need a meeting to talk about the idea and if it should be agreed.



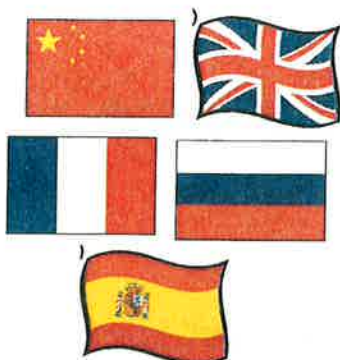
48. If a Country wants to get out of the Agreement

A Country can get out of this agreement by writing to the Secretary General. They will stop being part of the agreement 1 year after the letter has arrived.



49. Accessible Information

This agreement will be available in easy to understand formats.



50. This Agreement in other languages

This agreement will be printed in Arabic, Chinese, English, French, Russian and Spanish and will be equal in these languages.

Credits



This paper has been written, designed and produced for Department for Work and Pensions by the 'easy read' service @ Inspired Services. IS164/07. August 2007.



Artwork is from the Valuing People clipart collection and cannot be used anywhere else without written permission from Inspired Services.



www.inspiredservices.org.uk



This paper may be copied without formal permission or charge for personal or in-house use.

What is in this paper



1. This agreement

**Page
1**



2. What the words mean

1



3. The basic ideas agreed

2



4. What countries should do

4



5. Being equal

7



6. Women with disabilities being treated equally

7



7. Children with disabilities being treated equally

8



8. Giving people information about disability

8

What is in this paper continued

	9. Accessibility	Page 10
	10. Right to life	12
	11. Emergencies	12
	12. Being treated equally by the law	13
	13. Getting justice	15
	14. Being free and safe	16
	15. Not being tortured or treated cruelly	17
	16. Not being used or abused	18

What is in this paper continued

	Page
	17. Treating disabled people as people first 19
	18. Moving around 20
	19. Independent living and being a part of the community 21
	20. Getting about 22
	21. Saying what you want and access to information 23
	22. Privacy 24
	23. Respect for the home and the family 24
	24. Education 26
	25. Health 29

What is in this paper continued

	26. Services to help you recover	Page 30
	27. Work	31
	28. Standards of living	34
	29. Being involved in politics	35
	30. Sport and leisure	37
	31. Information	39
	32. Countries working together	39
	33. Making this agreement happen	40
	34. Committee on the rights of disabled people	41

What is in this paper continued



35. Reports by Countries involved

Page
43



36. What happens to the reports

44



37. The Committee and Countries working together

45



38. How the Committee will work with other organisations

45



39. The Committee Report

46



40. Meetings for the Countries involved

46



41. Keeping hold of all the reports and information

46



42. Signing the Agreement







47



43. Consent and Approval

47

What is in this paper continued

	44. Groups of Countries	Page 47
	45. When will the agreement start?	48
	46. Keeping to the agreement	48
	47. Amendments and changes to the Agreement	48
	48. If a Country wants to get out of this Agreement	49
	49. Accessible Information	49
	50. This Agreement in other languages	49
	Credits	50

DEPARTMENT OF DEVELOPMENTAL SERVICES

OFFICE OF LEGISLATION AND COMMUNICATIONS

1600 NINTH STREET, Room 322, MS 3-10

SACRAMENTO, CA 95814

TDD 654-2054 (For the Hearing Impaired)

(916) 654-1820, Fax (916) 654-1913

**Department of Developmental Services (DDS) to Work with State,
Federal Regulators to Address Sonoma Developmental Center
Non-Compliance, ICF Decertification****FOR IMMEDIATE RELEASE****Contact: Nancy Lungren
(916) 654-1820, (916) 616-8265 (cell)**

Sacramento, December 12, 2012 – The State Department of Developmental Services (DDS) issued the following statement today in response to enforcement actions taken by the California Department of Public Health (CDPH):

"Addressing this serious situation is my department's top priority. We will work with the federal Centers for Medicare and Medicaid Services and CDPH to ensure the Sonoma Developmental Center's care meets state and federal standards," said DDS Director Terri Delgadillo. "We have removed the Executive Director and the Clinical Director and taken disciplinary action against several employees, including job terminations."

"DDS is adding staff on residential units to ensure the supervisors on each shift are able to oversee and support the employees delivering direct resident care, and is bringing in outside law enforcement to oversee resident protective services" said Delgadillo. "We are contacting our residents' families to assure them of our continued commitment to making improvements. We are moving quickly to fix this center and protect our residents."

In response to resident related incidents at Sonoma Developmental Center (SDC), both the Executive Director and Clinical Director were removed earlier this year. DDS has launched a nationwide search for a new Executive Director to oversee the continuing reform at SDC. DDS is also entering into an agreement with the California Highway Patrol to oversee the Office of Protective Services, the facility's on-site law enforcement agency, until a permanent Commander can be hired.

In order to remain operational, DDS will file an appeal and agree to develop a Performance Improvement Plan with CDPH and CMS. This plan will include all necessary steps to ensure the highest quality services to residents and minimize any loss of federal funding for the services.

DDS has retained a regulatory compliance expert for SDC to provide on-site monitoring and ensure implementation of changes in the practices and procedures at the licensed health facility. Further, a Corrective Action and Quality Assurance Team consisting of state and national experts have reviewed the entire SDC care delivery system and are assisting in implementing ongoing improvements to ensure the health and safety of its residents.

DDS has reached out to its partners to help improve quality care at SDC including Disability Rights California (DRC), the state's protection and advocacy organization for people with disabilities. DRC has performed periodic unannounced visits at SDC to monitor resident health and safety and has agreed to increase its oversight of the facility and report the findings to the Department and CMS.

###

For more information, please contact Nancy Lungren, Assistant Director of Communications, at (Cell) 916-616-8265, (office) 916-654-1820, or nancy.lungren@dds.ca.gov. Visit www.dds.ca.gov for information about programs and services for individuals with developmental disabilities.